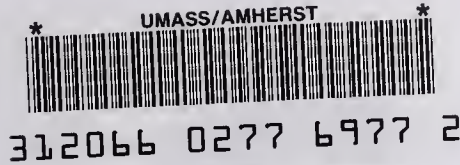


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POLICY BRIEF

Senate Post Audit and Oversight Bureau
Chair, Senator Cheryl A. Jacques

December 2002

The Gift of Life

MASSACHUSETTS CAN DO MORE TO PROMOTE ORGAN AND TISSUE DONATIONS AND REDUCE PREVENTABLE DEATHS

- Massachusetts currently has more than 2,600 people on the organ transplant waiting list. Eighty of these patients are children.
- In 2001, 656 transplants were performed in Massachusetts; however, 176 patients died while on the waiting list and another 57 were considered too sick to attempt the transplant.
- Other states have adopted innovative ideas to increase organ and tissue donations. As a result of new legislation, organ donations have increased 59% in Pennsylvania and 62% in Kentucky over 5 years. Massachusetts laws have not been updated in more than 15 years.
- Organ and tissue donation can make a significant difference. One organ and tissue donor can save or improve the lives of up to 50 people.

Background

Organ and tissue donation is the act of giving an organ or tissue, as a living donor or after a donor's death, to patients in need of healthy organs and tissues. The transplant can be a complete or even partial organ or tissue transfer from a donor's body to the recipient's body. There are no age limits for who can donate. Newborns (most states require parent or guardian consent for minors) as well as senior citizens can become donors, provided their organs or tissues are healthy. Tissues, eyes and often kidneys and livers can be donated from someone whose heart has ceased functioning. All organs and tissues can be donated from a person whose brain has permanently ceased functioning and who has been declared dead.

Organ procurement organizations are designated by the U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services or licensed under state law to coordinate all activities relating to organ donations in a specific geographical area. The New

England Organ Bank and LifeChoice Donor Services operate as the organ procurement organizations (OPOs) in Massachusetts. In addition to organ procurement and distribution, OPOs also provide educational information to the medical community and to the general public.

How does organ donation work? After a physician refers a potential recipient, medical personnel at a transplant center where the surgery can be performed evaluate and place the patient on a waiting list. The national criteria for placement on the waiting list vary for different organs. Patients who are waiting for an organ are listed by transplant centers on a national computerized waiting list. The United Network for Organ Sharing (UNOS), under contract with the Health Resources and Services Administration, maintains the list. Hospitals notify OPOs of all deaths and impending deaths. After an initial determination of the health of the organs, an OPO "donation professional" visits the hospital and provides support and information to help the family of a potential donor make an informed donation decision.

An OPO provides UNOS with medical characteristics of the donor and organs, such as "medical compatibility between the donor and potential recipient(s) on such characteristics as blood type, weight, and age; as well as the recipients' urgency of need; and length of time on waiting list." Because time can be a decisive factor in the success of transplants, preference is typically given to recipients in the same geographical area as the donor. OPO staff members coordinate the recovery with the hospital and transplant center and remain with the donor's family for support as long as requested.

An Act of Hope and Generosity

Restricted diet with no orange juice and no bananas. No more than one quart of liquid a day. Dialysis three times a week for 3-4 hours each time. These limitations were part of Miriam Gilman's life before her kidney transplant. Miriam, of Newton, Massachusetts, was diagnosed with lupus at the age of 13. Lupus is a disease in which the immune system is triggered to react against and ultimately attack the body's own tissues. Eventually, lupus attacked Miriam's kidneys.

After three years of dialysis, 18 surgeries, blood poisoning and three years on the waiting list, Miriam learned of the donation during a dialysis session. The kidney came from a 13-year-old boy who had expressed his desire to be an organ donor before he died and whose father honored that wish. The kidney began working immediately.

The transplant occurred in December 1995. Since then, Miriam has enjoyed her grandchild's birthdays and has even celebrated her own 50th birthday with 90 of her closest friends and family members. Miriam continues to take medication for lupus; however, she feels very healthy and active. Now that she has freedom from dialysis, Miriam and her husband travel extensively. Miriam, in an article for *Lupus World*, wrote, "I see organ donation as a social responsibility and an act of hope and generosity...I will be eternally grateful to the donor family that gave me the gift of life."

A Matter of Life and Death

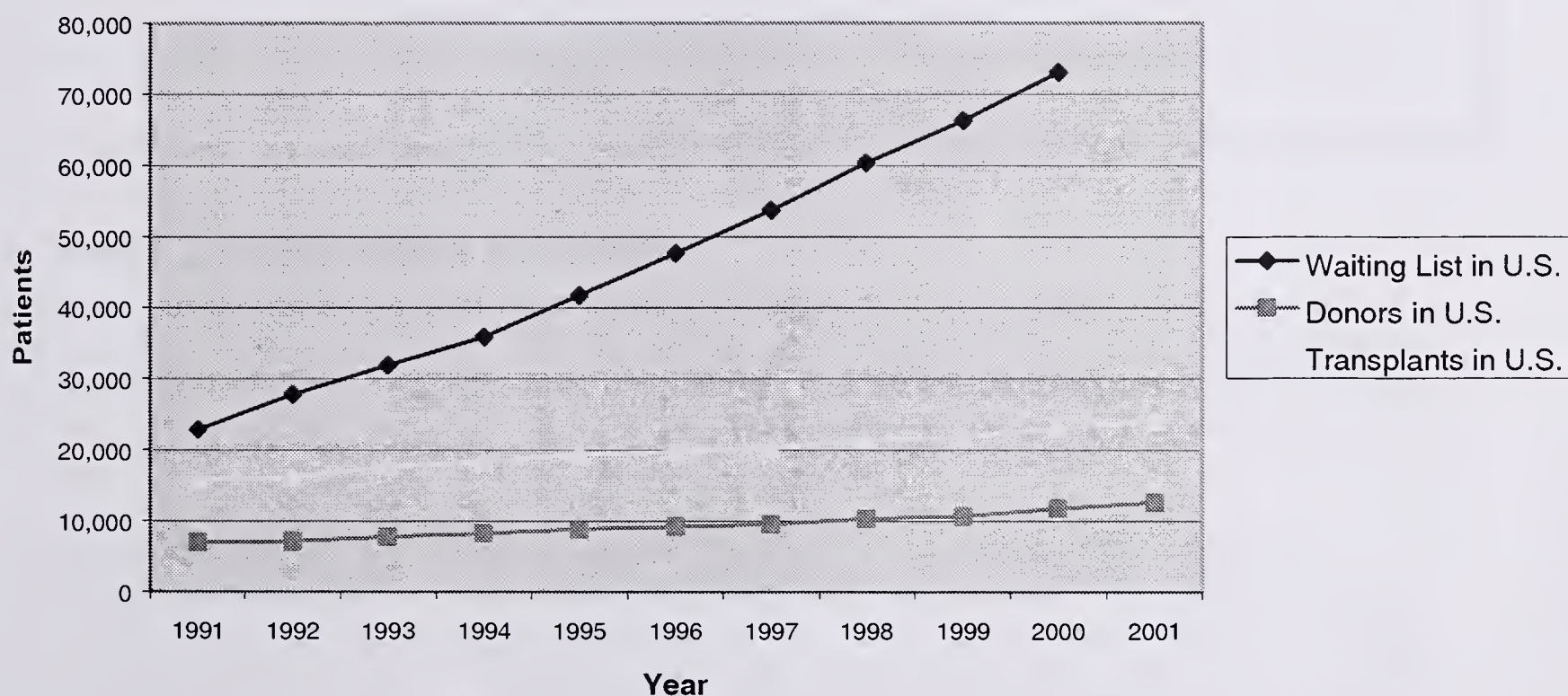
Nationally, there are approximately 80,000 patients waiting for an organ transplant, with a new name added every 16 minutes. Although an average of 63 people receive an organ transplant each day, another 16 people die on the waiting list daily because of the lack of available organs.

Making a Difference

Pennsylvania passed a law in 1994 establishing an Organ Donation Awareness Trust Fund. The law also created an Organ Donor Advisory Committee, which recommends legislation, educational programs and awareness programs in addition to overseeing the trust fund. Additionally, there are significant private initiatives such as the Gift of Life Donor (GOLD) Program with GOLD medals honoring donors posthumously and their surviving families. New Jersey and Delaware followed suit by passing similar laws in 1995 and 1998, respectively. Organ donations in these states rose by 59 percent between 1994 and 1999, compared to 14.6 percent nationally.

A majority of states have enacted laws within the past five years aimed at increasing donor registration and actual donations. By combining the most effective elements of laws from each state, Massachusetts can reduce the shortage of donated organs and tissues and provide model legislation for the remaining states.

National Donor Information



Source: The Organ Procurement and Transplantation Network

According to the Health Resources and Services Administration, there were 12,618 organ transplants performed in 1988 in the United States. In 2001, 24,086 were performed – almost double from 13 years earlier. Unfortunately, donations have not kept up with the escalating demand. The number of people requiring organ transplants will only increase as the baby boom generation grows older and life expectancy increases. Notably at risk are minorities who represent more than half of the patients requiring kidney transplants. To meet the projected needs, the number of donors must increase. Changes in state law could have the direct effect of saving lives.

A Second Chance

Linda Fall of Chelmsford, Massachusetts had her first heart attack, damaging 50% of her heart, at the age of 36. Between 1985 and 1991 Linda had five heart attacks. After each attack she was told she would not make it through the next one. Prior to an evaluation to determine if she was capable of surviving a transplant, Linda suffered her fifth heart attack. She was placed on the heart transplant waiting list in January 1992.

It was 4 AM on a Thursday morning in May 1992 when Linda and her husband Tom received the call that there was a possible donation. Knowing they had only two hours to get to the hospital, Tom attempted to run every red light. Linda somehow convinced him not to, for she was afraid they would get into a car accident – the last thing they needed at that time.

Linda remembers feeling excitement and nervousness; however, she also felt a lot of pain for the donor family. She considered them to be so special to think of someone else when they had just lost their young son in a car accident. “The donor families are the true heroes. My donor family is in my thoughts and prayers every day.”

Linda says she has been given a second chance at life, and she doesn’t take anything for granted. Linda maintains that she has not changed, but that her priorities have changed. Linda never misses an opportunity to let friends and family know she loves them. “If something happens tomorrow,” she says, “this was still 10½ years I would not have had.”

Federal Legislative History

According to the U.S. Department of Health and Human Services, the Uniform Anatomical Gift Act (UAGA), passed in 1968, “provided the legal framework upon which human organs and tissues could be donated for transplantation by execution of a document authorizing an anatomical gift.” Within four years, the UAGA was adopted by every state and the District of Columbia.

Transplantation became an accepted medical practice in the 1970s. Since then, the technology has advanced to allow more transplants and has resulted in a greater survival rate. Organ transplant recipients are living longer than ever before. According to the 2001 Annual Report of the Scientific Registry of Transplant Recipients, kidney transplants are the most successful, with a 95% patient survival rate at one year and an 89.2% rate at three years. Remarkably, living kidney donor transplants are even more successful. A heart transplant recipient has an 85.1% survival rate at one year and a 77.6% rate at three years.

Even the lowest single-organ transplant survival rates, which are for lungs, are still 76.4% at one year and 57.2% at three years.

A Family Matter

Tyke Crowley had been living with cystic fibrosis, a potentially fatal genetic disease causing lungs to fill with fluid and requiring routine hospitalization, when the beeper he continuously carried finally signaled some good news. At 28 years old, and after three years on the waiting list, he had a lung donor. However, almost a year after the transplant, Tyke's condition worsened, and he ultimately became dependent on an oxygen connection.

In March of 2002 his two younger sisters each donated a portion of their lungs. His recovery is slow; however he is becoming stronger and more active each day. After his schooling was interrupted by illness and hospitalization, Tyke is now working on his thesis and has only two classes remaining before he graduates with a joint Master's degree in Urban and Environmental Policy and Civil and Environmental Engineering from Tufts University.

Recognizing the importance of and need for additional regulation, the National Organ Transplant Act (NOTA) was passed in 1986 to develop revised policies on procurement, allocation and transplantation of organs. NOTA established the Organ Procurement and Transplantation Network (OPTN), funded by the Department of Health and Human Services, to develop a standardized protocol for determining patients' medical status and subsequently their eligibility for placement on the waiting list.

More recent federal regulation was adopted in 1998 with the Conditions of Participation and the Organ Donor Leave Act. The Conditions of Participation regulation requires the Centers for Medicare and Medicaid Services' Hospitals to notify OPOs of all actual or imminent deaths in order to ascertain if the individual's organs and tissues may be donated. The Organ Donor Leave Act allows up to 30 days paid leave of absence to a federal employee who becomes a living organ donor and up to seven days paid leave to a federal employee who becomes a bone marrow donor.

Current Massachusetts Laws and Regulation

Presently, Massachusetts requires that donor information be included with a driver's license renewal notice, according to M.G.L. ch. 90 §8D. The Registry of Motor Vehicles (RMV) complies by incorporating a single question into the driver's license application. The RMV personnel are not required to ask if an applicant would like to become a donor or to provide additional materials. This law does require the registrar of motor vehicles to make available a decal to be placed on the driver's license signifying an intention to donate; however, the record of who agrees to become a donor is not employed for any purpose other than generating the number of potential donors.



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The current Massachusetts organ donor laws, M.G.L. ch. 113 §§ 7-14, which are actually the adoption of the UAGA, deal primarily with who can donate and how. Anyone 18 years or older and of sound mind may make an anatomical gift through a will or a document signed by the donor and two witnesses. A living donor must have signed a document along with at least two of the physicians participating in the transplantation who have examined the donor.

Massachusetts law also requires that a family member or a guardian be informed about the opportunity of authorizing a suitable organ or tissue donation, providing there is no notice contrary to the decedent's intentions and that the information would not cause undue emotional stress to the family.

Life Out of Tragedy

Lee Cohen of Franklin, Massachusetts was diagnosed with cystic fibrosis at birth and was severely ill until he was about two years old, when his condition stabilized. Despite a 1-2% deterioration of his lungs each year beginning in his teens, Lee remained active and completed college and graduate school.

When Lee was 29 years old, the doctor told him his lungs were functioning at only 25% of normal capacity, which is the threshold for being placed on a transplant waiting list. Although Lee felt well and was even working 50-60 hours per week, he agreed to place his name on the waiting list as "insurance." Soon after, his lungs began deteriorating rapidly.

In August 1997, Lee was hospitalized for 2-3 weeks and tethered to oxygen. Because he was unable to function alone at home, he was readmitted in mid-September. Lee was still in the hospital when he learned about a potential lung donation. At 30 years old, and after 7 months on the waiting list, Lee received a double lung transplant on October 20, 1997. The donor was a 17-year-old boy who had died riding a 3-wheeler ATV.

Lee was home 12 days after the transplant and began dating a college friend six months later. He eventually moved from St. Louis, Missouri to the Boston area, married his college friend and fathered twin boys. Today, Lee feels great and swims one mile every day.

In 1983, Massachusetts established the Advisory Council on Organ Transplants, which has responsibility over the Organ Transplant Fund and the coordination of transplant activity. Currently, taxpayers are offered the opportunity to donate (on their state income tax return) to the fund, which assists Massachusetts residents with all or any part of the costs of their uninsured transplants. According to the Massachusetts Department of Public Health, the average donation to the Organ Transplant Fund is \$4.30 and total donations have ranged between \$180,000 and \$270,000 annually. Under M.G.L. ch. 17 §15, the Council is required to meet at least four times a year. However, according to an independent study conducted in February 2002 by the State Auditor, the Council has met only once in the last 15 years.

State law mandates that hospitals record information for each donation including the name of the donee, the organ or tissue donated, and the name of the person granting consent and their relationship to the decedent. According to M.G.L. ch. 113 §8, the Commissioner of the Department of Public Health is required to "issue an annual report summarizing and

evaluating the data collected.” Because of the recent federal legislation, Conditions of Participation, and the fact that OPOs actually keep track of this information, this law has become archaic and unnecessary.

Also, experts at the New England Organ Bank are concerned about procedures in hospital emergency rooms. Presently, organ donations are more typically addressed in intensive care units. The lack of knowledge about emergency room procedures regarding donations may be an impediment to increasing organ donation rates.

Several bills on organ donation were filed during the 2001-2002 legislative session. Representative Thomas George has championed the issue for four years, and just last month, the House of Representatives endorsed the creation of a donor registry. Representative George’s bill, House Bill 5246, is currently pending before the Senate Committee on Ways and Means. House Bill 5246 would:

- Create a registry of citizens who have documented their intention to become a donor;
- Include organ donation information in the required driver education and training courses; and
- Require the RMV to make available educational materials provided by the New England Organ Bank at all RMV branches.

The Koh Initiative

Dr. Howard Koh, Commissioner of the Department of Public Health, recently established a comprehensive donor initiative at nine area hospitals. As a result of this program, which teaches best practices to relevant personnel, organ donations increased 51% at the nine targeted transplant centers in the two-year period. Given the success of this pilot program, it is clear that Massachusetts will be able to reap tremendous rewards with other initiatives.

Strategies For Increasing Organ Donations

Massachusetts organ and tissue donation laws, written in 1971, have not been amended in over 15 years. Common sense legislation can bring Massachusetts laws up to date and can save lives.

For example, Massachusetts does not have a donor registry, a list of individuals who have given consent through a common channel such as the RMV. Although a registry listing does not automatically equate to actual donations, it does indicate an individual’s intention to donate. Registering as a potential donor can be done easily and conveniently, for instance, when applying for a driver’s license. Although the RMV currently places a decal on the drivers’ licenses of Massachusetts residents wishing to become donors, the computerized records are not available to any other agency, including the New England Organ Bank and LifeChoice Donor Services. A registry would enable the regional OPO to access the information in order to learn whether a patient had already expressed his commitment to donate organs. In many states, a previously expressed wish to donate, via the registry, a

signed donor card, a living will, or other means, can be a legal authorization for organ donation that may not require additional family consent.

At least 16 states have created a donor registry. In addition to documenting an individual's intention, a donor registry also assists states in tracing the impact of public awareness and education campaigns and of other initiatives to increase registration and donation rates.

Education and public awareness are key components to increasing anatomical gifts. Organ and tissue donations are surrounded by misconceptions; for instance, some people fear that doctors do not provide the highest possible care to someone they know is an organ donor or that families can be charged for donating organs. Proven strategies can address these misunderstandings. For example, Texas organizations have helped to educate the public through initiatives such as organizing a program in which heart transplant recipients visit schools on Valentine's Day, holding one of the largest road races in which many transplant patients and donor family members participate, and encouraging religious communities to host a National Donor Sabbath celebrating life and promoting donation.

States at the Forefront

Across the country there is clear evidence that when states have reformed their laws, the results have been positive.

- The Florida Legislature established a donor registry in 1995. By 2001, there were more than 2.8 million Florida residents listed on the registry.
- Due to 1993 Illinois legislation concerning donor education and the creation of a donation advisory panel that coordinated a multimedia campaign, more than five million residents are registered to be donors, and actual organ donation in Illinois has increased 54%.
- In 1998, Michigan passed a statute authorizing a donor registry and an innovative enrollment process that included prepaid postcards and Internet sign-ups. By the year 2000, the number of registered organ donors had increased by more than 1,000%.

Findings

- Current Massachusetts laws regarding organ and tissue donation are outdated and in need of reform. Massachusetts has a significant opportunity to learn from other states.
- Presently, despite an individual's expressed desire to donate, a family can still refuse to honor the patient's wishes. Thirty-nine states have enacted laws treating an intention to donate by certain means as an advance directive that does not require further consent.
- Unlike 16 other states, Massachusetts does not have an organ donation registry. Because the RMV does not currently allow access to the records of declared donors, the ability of the New England Organ Bank to work with families is hampered.
- The State Advisory Council on Organ Transplants is required to meet four times a year. According to an independent study conducted in February 2002 by the State Auditor, the Council has met only once in the last 15 years and a single employee within the Department of Public Health handles the daily operations of the fund. Because the local OPOs presently coordinate the donation and transplant activity as required by federal law, the Council in its current authority and purpose has become outdated.
- The Registry of Motor Vehicles is an underutilized resource. Given the department's frequent contact with state residents and the public's awareness of it, the RMV can be a key player in distributing organ donation information and in providing an opportunity for Massachusetts residents to enroll as a donor in the registry.

Recommendations

Donor Registry

- First and foremost, Massachusetts must create a donor registry since this is the first step to increasing donor rates. Organ donation authorities should be able to access the registry 24 hours a day via a secure Internet connection. A registry, controlled by the RMV, would allow the New England Organ Bank and LifeChoice Donor Services to immediately access information regarding a decedent's donation wishes, thereby facilitating the donation process and increasing the chance of a successful transplant.
- The RMV should explore allowing individuals to join the donor registry when they are applying for or renewing a driver's license via the RMV website.
- A previously expressed intention to donate, such as placing one's name on the registry, signing a donor card, a living will or a similar document testifying to the decedent's wish to donate, should be considered a legal authorization for donation. This evidence would be considered an advance directive and would not require additional family consent.

Advisory Council

- Given that the Department of Public Health and the current Advisory Council on Organ Transplants do not comply with the statute regarding quarterly meetings and given that coordination of organ donation and transplantation activities is now conducted by the local OPOs, the Advisory Council should be abolished. The Commissioner of Public

Health should retain the power to distribute monies in the Organ Transplant Fund and can continue to provide leadership on organ donation in many ways.

Registry of Motor Vehicles

- The Registry of Motor Vehicles personnel should ask individuals whether they want to register as potential donors and otherwise promote organ donation.
- As the RMV explores standardizing driver education curriculum, they should work aggressively to incorporate organ donation into public and private driver education and driving safety courses. Local OPOs could play a key role in developing the organ donation segment and in providing the information.

Department of Public Health

- The New England Organ Bank and LifeChoice Donor Services should work with the Department of Public Health to explore ways of conducting a study of practices within hospital emergency room departments in order to discover what procedures may enhance or impede a family's opportunity to donate. Currently, the donation process is typically prompted when an individual is in the intensive care unit. Because not much is known about possible donors in the emergency room, donation rates may increase once emergency room practices are understood.

Public Incentives

- The Governor of Massachusetts should present a Gift of Life Donor Medal to families of donors at an annual ceremony coordinated in conjunction with the New England Organ Bank and LifeChoice Donor Services. This could be held during National Organ and Tissue Awareness Week.
- Massachusetts should provide 30 days of paid leave to state employees who become living organ donors and seven days of paid leave to state employees who become bone marrow donors.
- Donor cards and information about organ and tissue donation should be included in the Group Insurance Commission's annual enrollment for state employees and retirees.

